The Experience of Long Term Opiate Maintenance Treatment and Reported Barriers to Recovery - A Qualitative Systematic Review

Short Title: The Experience of Long Term Opiate Maintenance Treatment: Systematic Review

Key words for indexing: Opioid maintenance, qualitative research, systematic review, methadone maintenance treatment, client experience

Abstract:

Background/Aim: To inform understanding of the experience of long term opiate maintenance and identify barriers to recovery. **Methods:** A qualitative systematic review. **Results:** 14 studies in 17 papers, mainly from the USA (65%), met inclusion criteria, involving 1088 participants. Studies focused on methadone prescribing. Participants reported stability, however, many disliked methadone. Barriers to full recovery were primarily 'inward focused'. **Conclusion:** This is the first review of qualitative literature on long term maintenance, finding that universal service improvements could be made to address reported barriers to recovery, including involving ex-users as positive role models, and increasing access to psychological support. Treatment policies combining harm minimisation and abstinence orientated approaches may best support individualised recovery.

Introduction

Within the UK context, recent [1] guidance suggests that a minority of problem opiate users have been excessively retained in treatment, and there is a view that clients may have been allowed to drift into long term maintenance once stabilised [2]. For the purposes of this review, long term maintenance has been defined as clients being on a continuous opiate maintenance prescription for 5 years or more. This is not necessarily perceived as problematic in other countries, as the European Union Drugs Action Plan for 2009-2012 emphasises a core aim of reducing drug demand, through focusing on prevention and treatment, including harm minimisation rather than abstinence orientated approaches [3] . However, in contrast to the harm minimisation approach, there has been a move in the United Kingdom to promote recovery from both illicit drug use and substitute maintenance prescribing, in order that individuals move towards a drug-free lifestyle. The recent ten year UK government strategy [4] put emphasis on treatment exit, social reintegration and recovery [1,5]. This new strategy, emphasised the focus on recovery in terms of 'supporting people to live a drug free life'. This approach may bring the UK into line with abstinence orinetated tretament approach of America, where a greater proportion of treatment services focus on inpatient detoxification and long term residential rehabilitation [6,7]. Evidence does suggest that substitution treatment is associated with prolongation of time required to achieve abstinence [8]. So, whilst between 30-50% of clients achieve stability on prescribed medication [9], less than 10% in the UK exit treatment abstinent [10].

There is little clarity regarding the concept of recovery. Wider definitions of recovery were formalised in the UK in 2008, by a group of experts convened to reach consensus on a 'vision statement' in preparation for the UK strategic reemphasis on recovery as a treatment goal [11]. This statement recognised recovery as a process, but invited further exploration about what recovery might mean for drug users themselves.

The role of long term maintenance prescribing in promoting recovery is contested. The harm minimisation approach may view maintenance prescribing as an end in itself, promoting stability and safety, whereas, an abstinence view sees prescribing as a short term intermediate measure prior to detoxification. This review sought to synthesise the published literature regarding opiate user's own views and experiences of long term maintenance in different contexts internationally, building on recent work focusing on quality of life in methadone maintained patients [12,13] Further aims were to explore qualitatively reported barriers to recovery, purposefully drawing on literature from across diverse historical timepoints; to synthesise understanding about the factors that may prevent individuals from achieving abstinence; and to draw out implications for current treatment services, thus contributing to the abstinence vs. harm reduction treatment debate on treatment approaches.

Methods

The full study protocol is available on the PROSPERO database, a prospective register of systematic reviews [14]. Comprehensive searches of EMBASE (Ovid), CINAHL (EBSCO), PsychINFO (Ovid) and MEDLINE (PubMed), databases were undertaken; limited to qualitative study design. Index terms describing opioid addiction were combined with index and free text terms describing maintenance therapy. See figure i.

Inclusion and exclusion criteria

Included:

- Opiate users' or clinicians' views on the experience of long term maintenance treatment
- Qualitative studies or studies including qualitative methodologies

Excluded:

- Non-English language

Search and retrieval of texts

- Duplicate references removed
- Records divided between CN & AB
- Titles then abstracts screened independently by CN & AB
- Full texts reviewed by CN, AB and VM. Throughout the process, reviewers discussed uncertain cases, until either consensus on inclusion was reached.

Data extraction
A comprehensive data extraction form adapted by the lead author according to Cochrane guidance [15], was used to capture key study characteristics and findings . This form extracted concrete study characteristics such as sampling approach and study design, but also summarised key qualitative themes identified by the authors of the papers.

Quality assessment / critical appraisal
Assessment of study quality was carried out independently by three reviewers (CN, AB & VM), using the CASP checklist [16], consisting of a screening question and eight detailed questions to assess methodological quality. A summary of the number of quality criteria (0-8) that each study was judged to have met is included in table i, (further details available from the author) and notes were kept on areas of methodological strength or weaknesses. Where papers reported on different aspects of the same study, defined here as linked studies, ([17,18]; [19,20], [21,22])**,** the highest number of quality criteria met in each paper are reported.

Data analysis and presentation of findings
Since this review sought to synthesise qualitative data, a mixed methods approach was adopted [23], using summary tables to report on participant and study characteristics, combined with a qualitative interpretative analysis of outcomes relevant to the review [24]. The qualitative interpretative analysis consisted of initially identifying first order themes identified by the authors of the papers, themes were then synthesised across papers to develop second order themes, before a final stage of analysis where interpretation of data across all of the studies was undertaken prior to reporting. Reflection and reiteration of the interpretative analysis were discussed at team meetings and through repeat readings of the results. CN, AB and VM all examined emergent interpretative findings to verify the relevant outcomes to be reported upon, and to ensure plausibility of the analysis [24]. Data from included full text articles are thus synthesised descriptively and analytically, organised around thematic headings inductively derived from the study data (first order coding) and interpretative headings defined by the reviewers (second and third order coding, see figure ii).

Results

A total of 3,545 studies were identified, and 3,245 abstracts were screened for eligibility after duplications were removed (see figure iii, Prisma diagram [25]. 3200 exclusions were made at this stage. 45 full text articles were assessed for eligibility and 28 were excluded at this stage. 14 studies, reported in 17 papers, met all inclusion criteria and were included in the review.

Study and sample characteristics

See table i.

Methodological quality

The median rating for included studies, based on the number of methodological criteria met, was 4.5 (range 0-7; mean 4.14). 3 studies were judged as poor (were judged to have met 0-2 criteria), 5 studies were moderate (3-5) and 6 studies were judged as good, meeting 6-7 methodological criteria. No studies met the maximum of 8 criteria. On the basis of using the CASP critical appraisal tool, methodological quality of the studies could therefore be judged as moderate to good overall. However, many of the studies were judged not to have reported adequately on fundamental criteria, such as data analysis, as papers often did not explain how findings were arrived at or what the formal process of qualitative data analysis and verification entailed. Other poorly described criteria were recruitment strategy, with little or no discussion of the choice of strategy and it's appropriateness to meeting the research aims; and the relationship between the researcher and researched, which was often not acknowledged at all, with little consideration of the impact on data collected.

Results reported here present a narrative synthesis of outcomes relevant to the review, drawing on first and second order themes developed. The interpretative analysis had identified the reported themes as being the most heavily weighted in terms of their inclusion across all papers included in the review.

The experience of long term maintenance

Positive benefits - stability

When asked to reflect on starting maintenance treatment, participants within the qualitative studies indicated an initial phase, surrendering the old drug life, and accepting a new identity as a 'patient' [26]. Meeting the main aim of maintenance treatment, service users reported a decrease in illicit drug use [27], with the likelihood of abstinence from heroin seeming to increase over time [28]. Other benefits of methadone maintenance treatment, highlighted by Neale [27], included avoidance of withdrawal, improved diet and increased weight, and improved sleep. Many reported moving away from crime [26] and cessation of harmful behaviours such as prostitution.

Relief at not having to think about drugs all the time was reported, with a shifting of personal responsibility for scoring to an external locus of control (reliance on treatment services for medication) [26] [13]. In a similar way, some reported being no longer dominated by the direct consequences of drug use, such as financial problems or a need for drugs [13].

Increased self-care

Others described maintenance as allowing a period of 'self care'. Thus, the focus on using drugs moved away from abuse of the body, towards inward reflection, self-care and healing. However, this was not the case for all, as many reported co-morbid addictions, particularly to alcohol [21]. Some participants [27] reported increased self esteem and feelings of self-

respect and confidence whilst taking prescribed methadone, which contributed to the care they afforded themselves.

Re-Focus on other life commitments

Attention is drawn [26] to the different meanings of 'work' expressed by ex-heroin users, where 'work' might previously have involved a combination of crime and possibly paid employment to buy drugs. During maintenance treatment, 'work' regained its conventional status and the level of paid employment rose. This was an important factor connected with good quality of life for those on maintenance treatment [13]. Others described a process of relinquishing the former heroin-using lifestyle and adopting other replacement activities – rediscovering 'conventional' life and finding enjoyment in mundane tasks again, such as housework [26]. This finding is supported by [27] who found that maintenance treatment allowed people time free from the worry of scoring illicit heroin, thus having more time to dedicate to other things, such as involvement with children or paid employment. Similarly, other participants [26] reported a regaining of pre-heroin interests, or developing new interests.

In a women only study [26], participants, many with children, were in relationships with spouses who were also in treatment. Rehabilitation meant a regaining of more traditional roles – a focus again on being a partner/mother and caring for children [13]. Enjoyment was experienced as socialising with the 'straight' world and being able to move away from past lives of prostitution and crime. There was a sense of rebuilt self- esteem gained from engagement with normalised social roles. This was supported by Vigilant [22], who identified four simultaneous 'recoveries', one of which concerned reparation of family and friendship networks, previously severed during the period of heroin use.

Negative impacts – dislike of methadone and the continuation of addiction

Some participants would have preferred to remain on heroin, if it were available and clean [26]. This links to an often negative conceptualisation of methadone [17]. Participants reported just as much, if not more problematic dependence to methadone as heroin, and that methadone created as many problems as it solved [27] [13]. This view of methadone as an addictive drug contrasted with that of treatment staff, who saw methadone as 'medication' [21]. Participants however viewed methadone as stigmatising [13], and preventing reintegration with the social world. This suggests that, for some, the experience of long term maintenance may be negative and conflictual. Participants were 'caught in a trap' of medication from which it was difficult to see a way out.

Side effects of methadone

The studies reported a wide array of side effects of methadone. Some participants reported increased perspiration, tiredness/drowsiness, and constipation and for many reduced libido

[26]. Others reported personality changes [26], and expressing a preference for other substitute medication, such as subutex. Damage to teeth was also a commonly reported side effect [27].

Long term goal of eventual abstinence?

Despite being in treatment long term, most clients suggested that their main goal was to 'get off drugs', including methadone [13,29]. Some [17] described having 'slipped into' long term maintenance, i.e. they had entered treatment with the goal in mind of getting off heroin, and had never intended to find themselves many years later consuming methadone as a substitute. For many others though, methadone was viewed more positively, as part of a 'recovery journey' or process. In this sense, recovery was not viewed as an end-point, but as a long term project of which substitute prescribing was an integral part in gaining stability [21], or an end point in itself. This was supported by clinician views, which reported that long term maintenance, not abstinence, was the preferred option for most patients, suggesting uneasiness amongst clinicians about some clients' abilities to successfully detoxify and remain drug free [30].

Barriers to recovery:

See figure iv for an overview of the thematic interpretative analysis findings, reported in detail below.

Inward focused barriers

Motivation and loneliness were identified as important barriers [26]. Some reported less confidence when prescribed methadone than when they were on heroin. Heroin had promoted self-esteem and masked underlying problems [21]. Fear of abstinence was conceptualised as the fear of being 'emotionally raw'[20,31], or having to deal with emotions without the cushioning effect of either heroin or methadone. Many clients could not remember a time in their lives where they had had to deal with emotions in a 'raw' state.

Both staff and clients considered reducing methadone to be extremely difficult [32], particularly dealing with psychological difficulties, feelings of loss (of the 'crutch' of methadone), anxiety, life stressors, and the resurfacing of feelings. Concern with physical difficulties was less strong, although *fear* of withdrawal symptoms was important [18,21]. User reports of methadone being highly addictive and likely to cause severe withdrawal were common and there was a belief that methadone was worse to withdraw from than heroin [27], [20].

The removal of the emotional 'buffer' of methadone meant that some participants reported a difficult hyper-emotional state [20]. Indeed, inadequate diagnosis of mental disorders amongst drug users may be a contributor towards recovery failure, and relapse [33]. Fear of life without the stability and routine of taking methadone also acted as a barrier to recovery [20]. Other aspects of recovery that needed addressing [22], included co-morbid addictions, other physical and mental health issues, dealing with 'self-loathing', and coming to terms with 'catalyzing events', such as childhood trauma.

It is suggested that the establishment of a non-addict identity is key to achieving recovery [34]. A narrative approach showed how this reconstructed identity may be less about the intrinsic nature of recovery from drug dependence itself, and more a reflection of the socially constructed nature of narratives developed due to immersion in drug treatment culture. In this sense, a refusal to reconstruct one's identity according to the conceptualisation of treatment services of the drug user as a 'patient' may represent a barrier to recovery.

Social barriers

There were difficulties with establishing a non-drug using network of friends, and severing ties with existing drug-using networks - a factor associated with relapse [33]. Staff views [32] suggested that outside social support, from partners, family and employment, all critically supported recovery.

Participants reported not being able to talk to others about their past lives, feeling 'in exile' from the normal world. Secrecy about the past may create a barrier in new interpersonal relations. Thus, there was a sense of being 'in limbo', where participants are caught between two worlds – cut off from their old drug-using world and yet unable to fully re-enter the abstinent world. As a consequence, there might be an over-reliance on other clients, or very dependent relationships with treatment staff. Clients who do well in treatment (e.g. ceasing illicit drug use) may find that their 'success' in itself, paradoxically, acts as a barrier to recovery [20]. This is hypothesised as being due to the positive esteem-building relationships that are built with treatment staff. This is rewarding and may represent a disincentive for moving away from maintenance treatment, since interaction with others outside may be limited. Similarly, other studies report that as individuals do well on maintenance and begin to engage with the conventional world, e.g. raising children, the stakes become higher and the risks of going through an unsuccessful detoxification have to be weighed against the costs and benefits of maintaining stability [21].

Interpersonal relationships may represent a barrier to recovery, possibly through complex interactions with individual fears [20]. Couples may attempt recovery together. Whilst this can be experienced positively, some suggested that they feared violent outbursts by

partners, and did not know how to cope with their own and their partner's withdrawal simultaneously [20]. Other authors have identified women reporting periods of abstinence followed by relapse corresponding to drug using patterns in their partners [33].

Negative role models may be a potential social barrier to recovery [20]. Participants are surrounded by 'models of failure', i.e. examples of other people who have tried and failed to detoxify. These negative role models act as a disincentive to recovery attempts. Visible models of those who have successfully recovery are often not available, as individuals have moved away from the environment of treatment services.

Structural barriers

Clients on long term maintenance are subject to multiple stigmas, having an additive effect, including ageing, being a previous drug addict, depression, poverty and being on methadone itself [35]. Multiple combined stigmas may represent a powerful barrier to recovery. Others [21] similarly discuss the interacting factors of social class and status, suggesting that those from the middle classes have more options (something to recover 'back to'). Individuals' self concepts may also interact with the experience of stigma [36]. It is suggested that participants with 'non-addict' or functional identities are better equipped to deal with stigma, and less likely to experience it as a barrier to recovery. However, those with negative self concepts or limited social resources, characterised as 'conflicted' users, may find being in treatment itself highly stigmatising.

The structural concept of a 'therapeutic impasse' may be a barrier to recovery, as clients and staff potentially work towards different goals. Staff may see clients as being 'psychologically impaired', suffering from physical or mental illness [29]. In stark contrast, clients may see themselves as part of a disadvantaged subculture. However, of note is that, over time, clients' views reportedly began to correspond more closely with staff views. This suggests that clients in treatment may come to accept the 'status quo' and engage with the identities suggested to them, in order to fit with the goals and ideals of the treatment system. Clients may therefore give up the goal of abstinence and accept the staff view of them as 'psychologically impaired', in need of long term maintenance. This is supported by others [17] [30], where clients reported treatment goals of wanting to 'get off methadone', whilst staff regarded this as a bad idea and likely to lead to failure. There is a social, cultural and economic divide between clients and staff within treatment services [29], suggesting that it is not surprising that views of the nature of addiction differ, since clients and staff themselves are worlds apart.

Similarly, qualitative evaluation of the 'formula story' of harm reduction [18], suggests that the (then) prevailing approach of treatment services in Denmark on harm minimisation has defined opiate users as chronic addicts, and so addiction as incurable. In this sense, the

dominant institutional approach of harm reduction is in itself analysed as being a barrier to recovery, as the system treats drug addiction as being a chronic incurable condition placing clients in the role of requiring palliative, rather than curative treatment.

Timing as a barrier

The concept of a 'critical point' or 'being ready' [20] to attempt recovery was important, thus recovery attempts at a time when a client is 'not ready' would be a barrier to recovery. Components to being ready include being supported by others, having structural supports in place, but also an internal motivation that 'the time is right'. Equally, 'not having anything else going on' in one's life was identified as a barrier to recovery [20].

Discussion and conclusions

This review is the first review to draw together qualitative literature focused on recovery from long term maintenance. In terms of the experience of long term maintenance, respondents reported being stable and able to focus on their own self care and healing. Not being preoccupied with heroin meant that participants were able to focus on other life commitments, such as caring for children or employment. Indeed, a recent review suggests that the sense of stability that maintenance brings results in significantly improved quality of life compared to using illicit drugs [12]. The 'emotional levelling' effect of methadone is seen on the one hand to impact negatively on quality of life, but on the other hand as an improvement compared to the negative emotions experienced when not on methadone [13]. The experience of stability can be seen to have partly been achieved through participants' acceptance of their 'long term condition', as a 'patient' [26], thus 'surrendering control' [19]. This relates well to seminal sociological work on 'the sick role' [37,38], whereby acceptance of addiction as a medical rather than social problem allows treatment of the 'disease' with medication. However, many participants reported a dislike of methadone and its' side effects. There was a feeling that addiction continued, but to a different substance.

Participants reported 'inward focused' barriers to recovery, including fear and dealing with emotions that were previously suppressed through heroin use. Social barriers were discussed, particularly in connection with difficulties in moving away from old drug-using friendship groups [39]. Structural factors related to 'the system' and institutional expectations were also analysed. Stigma, and the additive effect of multiple interacting stigmas [35] was important. A critical concept drawn out of this review was that of being 'in-limbo' between drug use and recovery [31]. Those maintained on a script long term sometimes felt that they were 'no longer a junkie but still an addict', attempting to reintegrate with the social world, but continuing to bear the stigma of addiction and maintenance treatment.

The findings of this review, specifically around barriers to recovery, may be considered in the context of Maslow's 'hierarchy of needs' [40]. According to this model, it is only once the basic physiological needs (such as for food and shelter) are attended to that there will be motivation to focus upon higher level needs. The sample of long term maintenance clients captured by this review may fall into Maslow's 'middle ground', having achieved stability on maintenance treatment and attended to basic physiological needs, but exhibiting fear about the prospect of full recovery, stemming perhaps from struggles with higher needs such as for self-esteem, and respect by others. Lack of achievement of higher level needs may result in further anxiety, acting in a circular manner to impede recovery. This suggests that clients need help addressing higher level needs, potentially through better access to counselling or psychological support [32]. This support should build self-esteem whilst recognising the important roles of friendships, peer support, and couple relationships, attempting to work with these to achieve goals and improve well being. Specific and targeted psychological support needs to be available during and after treatment to support the complex process of narrative reconstruction [34], as staff [32] raised the issue of support being suddenly 'cut off' as clients are discharged from treatment.

This review identified that visible role models of those who have successfully recovered are rarely available, but 'models of failure' abound. Many studies [32] [26] [29] highlighted the important role that recovered ex-users can play in treatment, in providing inspiring role models for others, and in contributing towards the self-actualization goals of ex-users themselves in terms of their own recovery process [21]. However, there may be difficulties in utilising recovered clients as role models, as their recovery may have depended on them moving away from treatment services [20].

The prevailing structural approach of harm minimisation services in Denmark was analysed as acting as a barrier to recovery [18]. A reformulation of this approach by treatment services, as currently in the UK, may better support some individuals in achieving recovery orientated identities. It can be observed that treatment policy in the UK has moved almost full circle, from externally driven abstinence, through harm minimisation, back to a renewed focus on abstinence and recovery, but with the new, although questionable, justification that this approach is service user driven.

Some studies [32] emphasised that not all clients wish to reduce their methadone and work towards abstinence. Thus, it may be appropriate for treatment services to accommodate both harm minimisation and abstinence based approaches [13]. A clinical report in 1973 [30] suggested the need for a treatment system based on harm minimisation, where client centred care could also support recovery. It is interesting to note that, nearly 40 years since this report, the UK appears to be continuing to resist an individualised treatment approach, with a new focus on abstinence and recovery dominating recent policy. A significant move forwards might be for services to move beyond the abstinence versus harm minimisation

debate, and adopt instead a middle ground integrated approach where there is a continuum between harm minimisation and abstinence as the ultimate treatment goal.

Study Limitations

The majority of studies identified were from the USA (65%), highlighting the derth of studies focused on client experiences of long term maintenance from other countries. The review therefore illuminates the client experience of long term maintenance and barriers to achieving recovery, although there may be a need to understand the culturally specific experience of long term maintenance of clients in different countries, since treatment systems and approaches vary considerably. For example, in the USA patients prescribed methadone for opiate addiction are required to attend licensed programs monitored by the Food and Drug Agency (FDA) and state methadone authorities, whereas patients in the UK may be prescribed methadone to be collected from community pharmacies or through 'shared care' arrangements with their General Practitioner. The treatment experiences of these patients may thus vary widely, and this should be considered when viewing the findings of this review, in terms of the cultural and social settings of patients.

Many of the studies identified for this review pre-date the recent UK recovery agenda as no date limits were set on database searches. Other identified studies are drawn from other countries where recovery orientated approaches have dominated. There are thus important lessons to be drawn from multiple cultural, historical and policy perspectives when considering the participant perspective of the actual experience of long term maintenance and client centred barriers to recovery, although these lessons should be caveated as being historically situated. A further limitation of the available literature identified by this review is that all of the identified studies focused on methadone only treatment. Thus the client experience of long term maintenance of prescribed buprenorphione specifically is a significant gap in the research literature that requires addressing through primary research.

Limitations of the search strategy employed by this review relate to the need to limit the number of papers that the team were practically able to synthesise. Applying a qualitative research filter (where available) to database searches may have excluded studies taking a mixed methods approach, that had not been classified and indexed as primary qualitative research. This is a shortcoming of the review, which may have missed qualitative evidence collected and reported alongside randomised trials. The review explicitly did not seek to synthesise the perspectives of out-of treatment opiate dependent individuals. Thus the views of those not receiving treatment currently, of those who have moved on from substitute prescribing, or of policy makers are not included within the review. Further work might aim to specifically report on the views and experiences of these currently out of treatment groups, to triangulate and add further insight to the findings of this review.

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